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Learning disability against itself: the self-injury/self-harm conundrum

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Accessible summary

This article compares the use of the term self-injury to refer to the behaviour of people with learning disabilities and self-harm to describe the behaviour of those without learning disabilities.

- It suggests the two types of behaviour to be more similar than usually believed.
- It presents evidence from the lives of a number of individuals with learning disabilities.
- The term 'career' is used to describe the way in which some people with learning disabilities build self-injury into their lives.

Abstract

The article begins with a critical look at the existing literature explaining self-injury by people with significant learning disabilities and self-harm by those with mental health difficulties. It suggests that the different conceptualizations are perhaps less distinct than might initially appear, and that behavioural similarities between those with and those without learning disabilities might be greater than previously believed. The notion of 'career' is presented as a means of explaining the process by which people with learning disabilities engage in self-injury and subsequently integrate it into their lives. Data are subsequently presented from a number of life histories of people with learning disabilities to illustrate the development of self-injury over the life course. The findings of the research indicate that the development and consolidation of self-injury over time conforms to the expectations of a career and provides reason to question the contemporary separate categorization of the behaviour of people with significant learning disabilities. The evidence suggests that the relationship between self-injury and learning disability is best explicable in terms of its intelligibility, rational behaviour in the context of the individual's life.

Keywords

Ambivalence, career, expertise, life history, self-harm, self-injury

Introduction

The conceptualization and categorization of violence against the self is complicated by the lack of overall consensus surrounding issues of inclusion criteria, behavioural description, degree of lethality and cultural appropriateness. People with learning disabilities, in this context, are identified variously as a discrete group outside of the categorization process (Walsh & Rosen 1988), included as a subsection of 'deviant-pathological' (Favazza 1996), not considered relevant to the study (Ross & McKay 1979) or mentioned in passing but not in any detail (Babiker & Arnold 1997). This article reports on a study of the relationship between people with learning disabilities and self-injury, raises questions about our current approach to conceptualization and categorization, particularly that the self-injury/self-harm dichotomy might be ill-conceived and proposes the notion of 'career' as a means of interpreting the phenomenon.

Learning disability and self-injury

Many writers employ different descriptive terms, arbitrarily or intentionally, though self-injurious behaviour is established in the context of learning disability (e.g. head banging or face punching) (Tate & Baroff 1966), and self-harm or deliberate self-harm syndrome in relation to mental health (e.g. cutting or burning) (Morgan *et al.* 1975; Pattison & Kahan 1983). The choice of term remains important, as it is based on differing conceptualizations of the behaviours and those engaging in them. The defining characteristics of self-injury in the context of learning disability comprise environmental reinforcement and stimulation, increased likelihood of biological origin, high frequency of engagement and its 'primitive' manifestation (Walsh & Rosen 1988). Other authors have emphasized the repetitive nature, the brief and protracted patterns, choice of body site (Thompson & Caruso 2002), lack of wilful intent (Baroff 1974; Fee & Matson 1992), absence of symbolic meaning, thought content and shameless lack of guile (Favazza 1996).

This conceptualization of self-injury draws heavily on the roles of behavioural psychology and biology as explanatory theories (Favell *et al.* 1982), psychoanalysis, once so influential, declining rapidly after being unable to answer its critics (e.g. Bachman 1972). A series of influential studies demonstrated manipulation of antecedents and consequences (Lovaas *et al.* 1965), recognized that the origins might be 'quite a different matter' from maintaining factors (Baumeister & Rollings 1976), differentiated possible motivating factors (i.e. attention seeking, escape from demands, tangible reinforcement, organic aetiology) (Carr 1977) and elaborated the principle of functional analysis (Iwata *et al.* 1982). The subsequent development of behavioural techniques located within a non-aversive life context framework have proven fruitful (Emerson 2001), but remain 'difficult to maintain in the long term' (Schroeder *et al.* 2002: xiii). Biology's contribution includes a model genetic disorder of self-injury (Lesch & Nyhan 1964) that continues to attract fervent interest (Harris *et al.* 2002; Kasim *et al.* 2002; Nyhan 2002; Tessel *et al.* 2002) and investigation of 'presumed' disordered neurotransmitter processes (Freeman *et al.* 2002: 107) relating to pain (Symons 2002), impulsivity (Zlotnick *et al.* 1999), and addiction (Sandman & Touchette 2002). Inter-disciplinary research, once considered only 'in complex clinical cases' (Luiselli *et al.* 1992: v), and reflecting an increasingly multi-factorial aetiological consensus (Schroeder *et al.* 2002), has influenced the piloting of a bio-behavioural model (Mace & Mauk 1999) based on identification of a number of possible subtypes of self-injury (Mace & Mauk 1995). This interprofessional collaboration is a laudable development, though there

may be other ways in which debate can be encouraged, our knowledge extended, and even alternative conceptualizations embraced.

Self-harm

Professional understanding of self-injury in relation to people with learning disabilities differs radically from that of self-harm, where comprehension of why people engage in such behaviours is located firmly in the sphere of life, particularly early-life, experience. There is a clear focus on childhood trauma, particularly sexual abuse (Romans *et al.* 1995; Warner 2000), though neglect, emotional abuse, communication difficulties, violence, loss/separation, parental illness and alcoholism are also significant (Arnold 1995; Walsh 1987). The emphasis is placed on how people go on to make sense of these experiences in later life, particularly unresolved feelings of low self-worth, self-loathing, guilt and shame. Babiker & Arnold (1997) suggest that the addition of a factor such as grief, betrayal, anger, powerlessness or anxiety might provide the catalyst for translation of these feelings into self-harm. Other writers have accentuated the impossibility of making sense of such life experience, so that self-harm initially provides a coping mechanism and later becoming integral to survival (Frost 1995).

The intelligibility of self-harm in the context of life experience, therefore, helps to prevent the identification of such behaviour as inhuman or other-worldly, something frequently associated with self-injury. The choice of behaviour, personified by laying a blade to the skin, is considered less primitive than thumping one's head against the sharp edge of the door frame, expectant, therefore, of a more complex explanation. Self-harming without experiencing physical pain might be possible through dissociation or 'zoning out', the effective detachment of the individual from the body to facilitate their behaviour (Ferentz 2002). The overwhelming psychic pain (Shaw 2002) might provoke a feeling of 'chronic invalidation' as a person, self-harm subsequently providing a means of coping with emotional overload or feeling alive in the face of emotional shutdown (Sutton 2005). Walsh & Rosen (1988) accentuate the cumulative effect of multiple trauma and the role of self-harm in playing out childhood *roles*, discharging tension, attracting attention, expressing despair and rage; the consequence may be a 'loss-vulnerable individual trained to be violent, impulsive, and substance-abusing, with a strong tendency toward self-abuse or self-victimization' (p. 66).

The separate categorization of self-harm from self-injury effectively confines people with learning disabilities as a discrete homogeneous group subject to different criteria for analysis. Even women with mild learning disabilities in secure settings, whose behaviours conform to self-harm, and where issues of gender, multiple cause and coping are significant, have been identified as 'challenging' and treated behaviourally (James & Warner 2005). Other studies have drawn attention to the high level of sexual abuse perpetrated against people with learning disabilities (Senn 1988), and the increased likelihood of the subsequent emergence of self-harming behaviour (Burke & Bedard 1995). Knowledge of people with learning disabilities experience and understanding of the world remains limited (Sinason 1992), some arguing that this can only be properly addressed by 'entering into the life world of the people in question' (Klotz 2004: 101). Others have tantalizingly suggested that the reasons for self-injury might not be so very different from the non-learning disabled (Babiker & Arnold 1997). This possibility permits us to consider the intelligibility of the behaviour in the context of the individual's life history, a process of engagement with self-injury that might be conceptualized as a 'career'.

Self-injuring as a 'career'

The incorporation of self-injury into an individual's life can be a gradual process, increasing in meaning to the individual over time and becoming slowly entrenched; arguments have been long established for the experience of learning disability to constitute a trauma (Sinason 1986), the resultant emotional distress being manifested behaviourally (Hollins & Sinason 2000). The key question addressed in this research concerns how people with significant learning disabilities and no use for the spoken word engage inexorably in a relationship with self-injury. This path might be considered in terms of a 'career', wherein 'it is not just what one *is*, but the whole panoply of responses from defining self and others who help shape the life cycle and the shifting sense of who one *becomes*' (Plummer 2001: 194). Some individuals with learning disabilities 'discover' self-injury, integrate their means of engagement into their lives, and subsequently come to be denned by others in terms of this relationship. Such a career is developmental, hence the need for analysis of the life history to reveal its progress, to demonstrate those 'interactional moments and experiences which leave marks on people's lives', what Denzin (1989: 70), perhaps excessively, refers to as 'Epiphanies'. Self-injury constitutes the 'social strand of (that) person's course through life', whilst its identification as a career draws attention to the 'changes over time as are basic and common to the members... though occurring independently to each of them' (Goffman 1961: 119).

The study

The criteria for inclusion in the research necessitated individuals having a significant learning disability, severe communication difficulties and engaging in 'repeated, self-inflicted, non-accidental injury, producing bleeding or other temporary or permanent tissue damage' (Schneider *et al.* 1996). The data collection methods comprised archive material (clinical case notes, professional reports and personal correspondence), brief periods of direct observation and a number of semi-structured interviews with parents and some professionals. A series of chronological case records were subsequently constructed and converted into comprehensive life-history accounts. The use of multiple sources of investigation, particularly the use of 'human documents', was intended to provide 'account(s) of individual experience which reveal the individual's actions as a human agent and as a participant in social life' (Blumer 1979: 29). Life-history studies ordinarily anticipate the individual's voice to be at the centre of the story (Atkinson 1998), though even when that voice is silent the stories of people with profound learning disabilities have been successfully told (Hewitt 2000).

Three local research ethical committees were successfully negotiated and access to both the group and case notes facilitated by the responsible consultant psychiatrist. The issue of consent was complicated by only one of the group communicating through speech; consequently, parents and legal guardians were the primary source of support in this issue. Initial contact was followed by further information and a written request for consent; 14 agreed immediately and two declined or failed to respond. One individual provided his own consent. A more comprehensive overview, discussion of the group profile, and consideration of ethical issues and general findings, is provided

elsewhere (Lovell 2003, 2004). The stories of only six of the 15 are discussed in this article, as the relationship of other members of the group with self-injury was considered qualitatively different (see discussion). Some biographical data are provided in Table 1 for introductory purposes. The names employed are not the real ones of the group, an attempt though not a guarantee of anonymity. Local dissemination of findings was achieved through a series of seminars for those involved in the care of the individuals concerned. Data were analysed according to the process of becoming a self-injurer, its development over time, importance to the individual and evident complexity.

Table 1 – Description of self-injury and biographical details

Name & DOB	Health Issues	Behavioural Description and Source	Background
Lesley Anderson b. 1980	Small stature; febrile convulsions til 5 years; scoliosis; limited vision; cleft palate; Wolf Hirschorn Syndrome; some cerebral palsy; elongated valgus feet (wears special corrective equipment)	'... constantly and continually pummelling her jaw with her fist ... short periods of silence but mostly whimpered or screamed ... beaten her face into another bloody pulp (community nursing notes)	Older sister and younger brother; continues to live at home with parents
Daniel Cotterill b. 1956	Small stature; microcephaly and craniotenis; restricted mobility and awkward gait; marked deterioration in mobility in early teens; worsening gait at 29 years; regular minor illnesses, infections and swallowing inedible substances	'self-mutilation of forehead by hitting it on objects ... excessive flexing of body on legs' (hospital medical case notes)	Three sisters, two older and one younger; admitted into hospital at 7 years old and remained for 30 years; parental contact ceased shortly after admission; has lived in an NHS Trust residential network since the mid-1990s
Sarah Houghton b. 1965	Mother contracted rubella during pregnancy; deaf and restricted vision; now blind following glaucoma; recurrent ear infections; autistic features; depressive illness	'Agitation and shouting, hitting side of face vigorously, shaking head, banging table' (assessment & treatment unit risk assessment)	Younger brother; residential school at 7 for 1 year; various institutions from late teens; independent sector residential network; returns to parental home in 1997
Janine Lewis b. 1969	Intermittent constipation/diarrhoea since bowel resected in 1984; erratic, heavy menstrual cycle; periodic weight loss; alopecia; bouts of cellulites; depression	'The head bashing, the bashing of the ears, the banging of the head with the back of the hands, kicking her shins, elbowing her hips' (interview with assessment & treatment unit staff nurse)	One of four children; lived with parents til early 1980s; admitted to institution til closure in early 1990s; fluctuated between various social service homes and NHS Assessment & Treatment Units; independent sector housing

Sam Morris b. 1975	Shingles and hepatitis as child; hyperactive til lost some use of left side – mobility difficulties since; constipation; cataracts from 11 years; periodic throat & ear infections; autistic features	'...attempts to hit himself on his face and head using his right and left arms ... will also try to hit his head against objects' (behavioural support team notes)	Older of two brothers; continues to live at home with parents
Alison Wilson b. 1968	Short but heavily built; impaired vision in right eye; external strabismus; 'unstable bowel' – constipation/chronic diarrhoea; left side hemiplegia; piedro boots & left knee calliper; slight contracture of left elbow & wrist	'chin hitting shoulders (sometimes with upper and lower teeth clicking together); hitting brow and nose with left hand; hitting right side of head ... more frequent and severe over time' (speech and language therapy report)	Older and younger brothers; continues to live at home with parents

Findings

The data presented in this section are divided into five parts, each demonstrating a different facet of self-injury and cumulatively revealing the process by which it became integrated into the lives of the group. The first part concentrates on the ways in which self-injury developed over time, specific life events serving to remind the individual of how effective tried and trusted means of expression can be during such circumstances. The second part provides a description of the contemporary relationship between individual and behaviour, the requisite technical skill for effective engagement. This is followed in part 3 by further description, though this time of a selection of other behaviours engaged in, sometimes to expend energy; pass time or fulfil some other need. The variation in purpose that self-injury might serve, its seemingly paradoxical nature is addressed in part 4, and the final part looks at the role of anger, only occasionally the defining characteristic of an individual's violence.

Consolidation

The consolidation of self-injury varied according to individual life stories, though the data frequently suggested that there was a process involved and behaviours might come to represent greater significance during times of particularly difficult or even intolerable circumstances. Lesley Anderson's relationship with self-injury encompasses the conspiracy

of specific sets of circumstances spread throughout her childhood, notably at five and later during significant teenage years. Sarah Houghton unlocks the secrets of self-injury as a response to the incalculable frustration she experiences as a young child surrounding communication and education. Further disappointments, epitomized by the complete loss of her sight as an adult, demonstrate how a favoured physical response can provide a successful channel for expressing the mixed emotions that characterize grief. An illustration from the teenage years of Sam Morris, marked physical deterioration, suggests the significance of key life events serving to fuel self-injury, whilst professional reflections on the background of the maturing Janine Lewis provide evidence for a chaotic upbringing, one not inconsistent with an emerging self-destructive tendency.

The beginnings of Lesley's self-injury, according to her mother, are associated with her brother, 3 years younger, becoming more able than her, something she was extremely aware of, and was a point of additional importance, perhaps, because she then needed to work out how to deal with such disappointments:

Mrs A: ...when Lewis (lesley's brother) started walking, running around (becomes more softly spoken), she couldn't do that...and that's when she started getting mad and hitting and kicking, I think, because she wanted to do what her brother was doing...that's when she got angry...she used to bash, well, she punched her chin.

Lesley (14 years): ...there appears to have been some regression over the years, especially as her younger brother has grown up and overtaken her (clinical psychologist correspondence with county education department).

Lesley's primary physical difficulties, outlined in Table 1, were compounded by '...decayed teeth...proneness to chest infections, allergies, epilepsy, noise sensitivity' (community nursing notes), and, when she was 11 years old, 'major spinal surgery to correct kypho/scoliosis but didn't achieve effect' (physiotherapy report).

Mrs A: ...that's when I broke my arm. Cause my dad died that year...Three things happened within a month...(Lesley) had this back surgery done...they removed a rib out, encased four discs and put a rod in to try and straighten it...she used to, because of the pain and that, I think, she hit herself more.

She was locked in a body that frequently made life uncomfortable, accentuated her differences from others, and amplified her feelings of vulnerability; then, at 16, came sexual maturity:

Mrs A: (Thoughtfully) ...she was going from a young girl to a woman, and with that you have body changes and you have pain, like period pain...She knew there was things going wrong with her body...she wasn't eating properly, so it upsets her bowels, she couldn't go to the toilet, she got constipated...she's thinking, 'what's going on?'...a week or two before (her period) she'd start with all this really bad punching and kicking and crying.

Sarah, 7 years old, deaf and partially sighted from birth, makes astounding progress at a specialist residential unit, because of an improvised 'objects of reference' system, quite radical for the early-1970s:

Mrs H: She used to have a bag of things (and) each thing meant something...rubber balls with little bubbly spikes on...really tactile things to say what she wanted.

The unit closes a year later, Sarah returns home, attends a school for the 'severely educationally subnormal' (ESN[s]), and there is a rapid reversal in the self-help, social

and interpersonal skills gained. Mrs Houghton identifies it as a critical moment in her downward spiral into violence and self-injury:

Mrs H: (Sarah's teacher) wanted to take her shopping...and prepare the meal...(she) got frustrated with Sarah and Sarah knew...so she'd get frustrated as well...it just...ended as a riot...She was just sort of shaking...her feet were smacking the ground... throw herself back and banging her head on the floor...her whole body was, like, in a convulsion...she couldn't express herself before that, to be angry and frustrated, but then she'd suddenly learned how to do it.

Sarah's story encompasses numerous such disappointments, institutionalization at 15, two subsequent hospital closures, an independent sector placement and one with the deaf society before she returns to live with her continuously-involved parents. The final placement results in her biggest disappointment; her father and a Royal National Institute for the Blind (RNIB) assessment provide the brutal details:

Mr H: ...that was where she lost her sight there. We had to go there and tell them in the end, 'for Christ's sake, look, there's something wrong here'. They had everything they needed there...their own GP...why she didn't notice I don't know...said she'd got conjunctivitis...it were pretty quick... Sorry, gone. Could have done something but not now, too late for that.

Sarah (33 years): A common later consequence of rubella with congenital cataracts is a risk of glaucoma which manifested itself...her parents started to notice her sight was deteriorating she was referred to a GP who treated her for conjunctivitis. By the time the correct diagnosis was made the fluid pressure inside Sarah's eyes had already built up to an extent that she had now lost her sight in both eyes and is now functioning as deafblind (RNIB multiple disability services assessment).

Sarah's new world inculcates further suspicion of strangers, fear of new situations and the comforts of violence:

Mrs H: '...it was like Sarah said to herself that day, 'I've got you marked, you're one of them'...and she started hitting me and she'd never done, never any of that ...she wasn't violent towards me, and she was that day...it was as if she'd placed Lynne (1:1 worker) as one of the enemy...and from that day on our real trouble begins...it was just all out violence...where she was throwing chairs and that sort of thing.

A fall in the snow, physical deterioration and an inexplicable medical phenomenon conspire for Sam Morris to retreat from hyperactivity to a less mobile, self-contained and increasingly self-injurious lifestyle:

Mrs M: ...when that happened all one side went weak. That's the left side, it shakes...he just sort of altered...-when he had the fall...its just odd isn't it, for somebody who'd been running around a lot to want and sit and lie with a quilt.

Sam (13 years): Sam's behaviour has been extremely difficult during the last fortnight...inflicted several deep gashes to his forehead...not been eating very well and has cried (real tears) on a couple of occasions...face is badly swollen...has been refusing to walk around preferring to lie or sit (most unusual for him) (community nursing notes).

...appetite has fallen off in the last six weeks since the increase of his head banging behaviour...apathetic and less restless...some withdrawal and apathetic behaviour sometimes seen in adolescence in handicapped people with severe hyperkinetic syndrome (consultant child & adolescent psychiatrist letter to family GP).

Evidence of Janine Lewis's early life comes from a professional report that goes out on a limb and an interview with a staff nurse, who had known her from a child:

Janine (26 years): Janine used to be restrained in a rocking chair...strapped into a wheelchair to go out even though she was ambulant. These experiences will have had a marked influence on Janine's present difficulties...indicators of significant emotional distress of the kind often related to mistreatment (speech & language therapy report).

Basically unmanageable...quite wild...She was never used to being allowed to wander at home...confined in a chair to stop her ripping wallpaper and destroying the family home...She would smear (faeces) on herself, over the walls, on anyone else...if she could get hold of someone else's excrement...she would deliberately go into their (underwear)...there was no evidence to suggest she...had an individual personality, she was just a human being (who) presented with these behaviours (interview with staff nurse).

Expertise

The group acquired a certain technical skill in the build-up and subsequent execution of self-injury, which was evident particularly in its eventual physical manifestation but might be indicated by the escalating momentum. This expertise constituted the accumulation of thousands of hours of engaging and effectively refining those behaviours that achieve the desired effect; they all appeared to have perfected their chosen modes of violence. The imminence of a bout of self-injury might be accompanied by a visual clue, such as a physical sign of irritability, a particular facial expression or specific sounds. There might be a gradual change of mood, it might be a reaction to circumstances; the parents of three of the group describe such tell-tale signs. Mr and Mrs Houghton describe the gradual way in which Sarah's affinity with self-injury might rise to the surface, Mrs Morris's description pinpoints that time when Sam needs to engage, and Mr Wilson talks of Alison's rapid though systematic indulgence.

Mr H: '...you can sometimes see it starting over a couple of days...she's gonna get grumpy about something'. Mrs H: '..."the monster's crawling out of the pit", you can tell because her face changes'.

Mrs M: '...have that face where he's really mithered'.

Mrs W: '...she starts banging her feet...I move out of the room...she'll still continue doing it...she doesn't really give you any warning at all...she'll go 'byah, byah'...-she'll get up and bang the wall.

The manifestation of self-injury comprised a certain physical ability, a sometimes elaborate and convoluted routine, a degree of concentrated effort and variation in intensity depending on the satisfaction to be gained. Consider the following descriptions:

Janine (26 years): She groans (which) get louder as the hitting gets stronger, and with facial grimacing...gets more severe and harder when Janine is distressed (speech & language therapy report).

Sam (22 years): '...begins to slowly tap his foot...goes to banging his foot either harder on the floor or against objects...begins to bang his head against the back of his chair or on objects...banging his right arm and then on to using his left arm to hit the side of his head...his left fist to punch the side of his head...may begin screaming...the peak of his behaviour (behavioural support team report). Alison (24 years): '...hits herself on the head usually at the sides/temples...right or left arms, hands or fists, more frequently the right...When she uses her left arm she can make contact with either the arm held

straight or the fist with elbow bent...makes contact with her right arm it often makes a noise, which gets louder as the severity increases (speech & language therapy report).

Daniel (43 years): It begins with Daniel making low sounds, shaking his hands...becomes more intense with him jumping up and down and either tapping his nose or twisting his hair...he may commence headbanging, often taking himself into his bedroom and, whilst sitting on his bed, bang the back of his head on the wall (sometimes) he will close the door (interview with community nurse).

In effect, they all develop an individualized pattern of behaviour, which involves a certain routine, including most favoured times of day and the sometime need to engage in an uninterrupted, ritualized manner. Self-injury may be both a private and a public act sometimes requiring the attention and concern of others and sometimes requiring solitude.

Table 2 – Other behaviours contributing to the overall repertoire

Name	Additional behaviours
Alison	‘rocking and humming tunes’ (behavioural support team)
Daniel	‘combination of facial and hand mannerisms (medical notes) ‘he does a lot with his hands, self-stimulatory really ... he has a very definite ways of holding his hands to do it (interview with community nurse) ‘And also, one thing I’ve come across .. and I’ve seen him do it a few times – whereby he sits down and lets the top half of his bodyweight fall so his actually hits the floor (interview with community nurse)
Janine	‘rocking and overactivity ... paper ripping; (clinical psychology report) ‘marked hyperactivity] (GP correspondence to social worker) ‘eats soil and plants (assessment & treatment unit report) ‘seems to use her sense of smell to test things, often sniffing at things she holds; (speech and language therapy report)
Lesley	[... head rolling, clapping ... and hand shakes a great deal’ (community nursing notes)
Sam	‘...will spend time sucking at areas of the duvet’ (behavioural support team notes) ‘he constantly holds plastic toys in his hands and swirls around in circles’ (community nursing notes) ‘,,,he does a lot of banging his foot as well ... on his chair ... wanted the noise and he wanted that bang (interview with Mrs Morris)
Sarah	‘...favourite things being clicking balls. She likes the sound of the clicking and particularly likes blue or red ones to take to bed with her’ (case conference report) ‘comprehensive bouts of drinking (water); (consultant psychiatrist letter to GP) ‘strips off and rocks in her bedroom’ (clinical psychologist letter to consultant psychiatrist)

Completing the behavioural repertoire

The additional behaviours described in Table 2 were sometimes in evidence during bouts of self-injury, particularly when the desire was to be more vigorous and enthusiastic, whilst on other occasions might be for reasons of comfort, passing the time or self-stimulation.

Ambivalence

The ambivalence of self-injury refers to the way in which behaviours, pursued and consolidated over sometimes lengthy periods, can come to occupy such an integral role in the life of the individual that they can be employed for radically diverse purposes. It is initially demonstrated through Mrs Wilson's recollections of Alison's headbanging sometimes accompanying a particular tune, though she is less confident than the behavioural team about the reason. The subsequent comment about the requisite number of hits is described in a way that suggests great understanding, the emphasis being placed on this occasion on the routine rather than physical satisfaction. Numbers are also important for Sam Morris, firstly as a child in the apparent desire just to bash away the problem, and later in the more purposeful, selective, yet paradoxically less predictable ways in which blows are struck. Sam's complex employment of self-injury, ostensibly confusing because of the absence of a clear trigger or reason, though perhaps becoming clearer during a bout of illness, which reveals the behaviour's multiple, though shaded, purposes. Lesley Anderson, similarly, reveals contradictions in the emotional underpinning of her self-injury, its equivocal nature established early. The separation of the need for real hurt, albeit sometimes expressed arbitrarily and sometimes determinedly, is exemplified finally by Daniel, Janine and Sarah, all of whom occasionally sought refuge in that troubled heart of self-injury.

Mrs W: Its just like a habit. She can sit there and she doesn't make a murmur.. we used to say she's got things wrong, like London Bridge is Falling Down... so when she was in a bad mood she used to sing it, because she can hum tunes. And I think, oh aye, we're in for something...she sort of had it twisted, because when you're singing you're supposed to be happy... quite strange really. She does cry and she does the same things, but she does the same things when she's not crying...the banging never stops, oh it never stops.

Alison (30 years): humming continually to prevent conversation with self (behavioural support team notes).

Mrs W: Now the other day she banged her head three times on there (points to place on wall), Well she knows she does five, so she went up again, but instead of doing the extra two she did five again, as if to say, 'that wasn't proper, I'll have to do the right number'.

Sam (8 years): ...previously banged his head against walls, floors and tables but has lately added hitting himself with clenched fist or open hand. Occasionally the blows have been excessive, we counted 64 blows per minute recently' (social services progress review).

Sam (23 years): At first six hits, he was laughing at the actions staff were doing in the music session, then the next three were hard ones (behavioural support team notes).

Mrs M: He will sometimes bang his head or slap his face and he will laugh or just do it anyway. He'll try and head butt the door, sometimes he won't, you don't know. He can get off the chair laughing and still do it.

Sam's hospitalization because of a yet undiagnosed throat infection provides circumstances for self-injury, but things are never entirely as they appear. Self-injury as a response to pain, anxiety, fear, distress about the environment, for all or none of these:

Mrs M: '...he was head butting himself. He had every pillow...trying to guard him. He was butting the steel bars'. (Pause) It was because it was somewhere different as well...we had to lie with him and hold him tight on the bed with his quilt around him in between us. And he would have hated that normally...he was in so much pain...and he was frightened...lots of people will say, 'oh he mustn't be very well, he's ill'. But

sometimes its because he doesn't want to do what he's doing at that time...he can be laughing or chewing his quilt, holding a toy or a cushion. The minute you move him, he'll start...not always ...He will sometimes bang his head or slap his face and he will laugh and get enjoyment or just do it anyway.

Lesley (11-years old): ...appears to have no particular pattern to it; Lesley can be sitting quite happily on her mum's knee and then start banging her chin (referral to child support team). Mrs A: She'll be sitting watching telly, laughing, and all of a sudden she'll start crying and hitting herself...You're sitting talking to her and she's laughing like mad, and she just whips off and cries (and if) she was sitting by you, she'd throw herself against your body.

Variations in force hinted at issues of intentionality:

Daniel: ...he also uses his hand as a barrier sometimes -there's definitely times when there's a real head-butt at the wall, but at other times his hands seem to be 'in the way' (interview with community nurse).

Janine: Some days she does it very gently, and other days...she'll really kick her shin and the elbow will really go hard into the hip (interview with staff nurse).

Janine (26 years): ...targeting her head, shin, arms and hips...a habitual smack/kick which isn't very hard and doesn't have severe consequences...other type is more severe hitting/kicking herself and has resulted in hair loss, skin breaking down, bruising, lumps (social services review).

Sarah (33 years): ...could be settled in manner and then suddenly start to self-injure...when Sarah hits her head she might not use full force or corners of objects, she will use flat surfaces (minutes of assessment & treatment unit meeting).

Rage

This expression of real anger provides the final theme, that seemingly inexplicable rage that appears to be both a cardinal characteristic but evident only on certain occasions. The distress caused to Mrs Anderson by her daughter's very real demonstrable violence begins the section, the inconsolable manifestation of her self-injury provoking complicated conversations between parent and professional. Sarah's fury, according to Mrs Houghton, her mother, grips her like a vice and again reflects her despair at current life circumstances; Daniel's institutional history shows the early resolute engagement in headbanging, whilst his community nurse describes the contemporary anger that places him firmly in control. The relationship between Alison and her behaviour is also noted to embrace this notion of control, with the observation that this can be a fine line between in and out. Finally, Janine's more deliberate violence is complicated by her apparent sensitivity to the events, people and environment that surround her.

Lesley (10 years): ...prone to self-inflicted facial beating and to paw at her body and her legs, using both hands and feet...Tends to cry a great deal, often this in a crescendo form to a high pitched scream. She also has (long) periods where she displays sobbing, as if in pain (community nursing notes).

Clearly you are 'looking deeper', and in your words, 'stopping and thinking more, listening more, and trying to talk on a different level, with simpler sentences'. You have developed ways to deal with Lesley's anger' (correspondence from clinical psychologist to Mrs Anderson). Mrs Anderson is 'convinced that (there is) a very intelligent person inside', and "would like 'to get rid of Lesley's getting 'annoyed and angry'" (psychology report).

Daniel: ...there are times he shows frustration...anger...if he's not happy with life...then he's got to work it through or retire to his bedroom...nobody can control it...and if you look at him, its in his eyes an awful lot...he's got that look that says 'I'm doing this' (interview with community nurse).

Alison (21 years): On occasions Alison will appear to have limited self control over her self-injury. Alison becomes very aware of this (behavioural support team care plan).

Janine: The severe self-injury only occurs occasionally...really bashing to the point where the ears split, till they bleed. She won't stop...she gets in, she puts her hands to her face. She will bruise under her eye, because she pushes the hands into the nose and punches with it...She'll put the finger on the eye, but she doesn't gouge at the eye (interview with staff nurse).

Janine (27 years): ...susceptible to the mood of groups and individuals. 'Bad vibes' will lead to an increase in Janine's level of self-injury and general distress (social work standard assessment).

Discussion

The data suggested that some people with learning disabilities have a relationship with self-injury that is refined over time, contradictory and convoluted in nature, and central to the individual's identity. The degree of learning disability restricts the choice of method available, headbanging being simple, efficient and strikingly effective. The role of critical junctures, whether traumatic, enlightening and disaffecting, were significant, as were the frequently nebulous motives for self-injury, its multiple purposes, associated characteristics and peculiarly individual nature.

The self-injury 'career'

Such a career is not a thing that can be brilliant or disappointing; it can no more be a success than a failure (Goffman 1961, 119).

The individuals discussed in this article might be considered to have engaged on a self-injuring career, which involved the negotiation through stages of novice, regular and latterly serious. Self-injury was fundamental to their identity, they 'liked to do a bit every day' (Mrs Morris); its willful intent reflected moods, frustrations, physical distress, and enabled them to cope with difficult or even unbearable circumstances. They constituted core self-injurers, as opposed to those whose behaviour might be more peripheral to their lives; more ephemeral, strategic blows to the face to communicate needs and dislikes, but less integral to their being. Core self-injurers required a certain amount of activity, Alison's five rather than three bangs, the look in Daniel's eyes or Sam's facial expression indicating they 'meant business'. The occasional rigidity of Lesley and Sarah's anger, Janine's unfathomable despair suggested that pain might provide a safety valve during these moments. The sometimes complex mode of delivery necessitated the requisite combination of concentration and expertise to provide satisfaction, though, as with any other abuse of the self, there was always the risk of over-indulging. Specific incidents or critical junctures facilitated transition through different stages of the career, Sarah's relegation from the specialist unit, Janine's early experience, Sam's retreat from hyperactivity or Lesley's recognition of 'the way things were'. A more detailed exposition of the self-injuring career has been provided elsewhere in relation to Daniel (Lovell 2006),

facilitated by the long, empty hours of institutional life, though, according to his admission document, begun earlier. Daniel could modify the effects of self-injury by placing his hand between head and object, just as Alison might change her mind and turn away from the wall at the last minute. A number of possible, though not essential, characteristics of a self-injuring career are described in Table 3.

Table 3 – Characteristics of the self-injuring career

Characteristics

1. Occasional desire to satisfy a need for causing real bodily damage, characterized by real intent, oblivious to the attention of others and seemingly calculated in the required extent of physical damage
2. Behaviours having been refined over many years, though probably established early, and involving a degree of expertise in execution, such as in the build-up of energy and rhythm
3. Variation in the mechanics of self-injury: revolving around a preferred choice (head against wall; punch to chin, cheek or temple) and supplemented with other behaviours, either for variation or through necessity, such as when physically or mechanically prevented (shoulder against chin; heel against shin)
4. Repertoire of additional behaviours, varying from the intricate (finger flicking) to the seemingly pointless (rocking) (see Table 2)
5. Self-injury can be indicative of the discharge of seemingly contradictory emotions or states of being (happy, sad, angry), though significant and sometimes subtle variations according to desired effect (choosing a flat rather than pointed surface; reducing or increasing the energy level)
6. Self-injury might be clearly functional, as in the communicating of a want, for someone to go away or to enjoy the sensory consequences - but it might also reflect self loathing, emotional emptiness or extreme rage
7. Critical junctures might take the form of trauma in early life, recognition of one's limitations or differences from others, one major disappointment too far, apparent continuous rejection - these operate as a means of propelling the individual on to the next stage of the career, and, in effect, can confirm the individual's sense of self.

The rational nature of self-injury

Recourse to self-injury appears, therefore, to be largely a gradual phenomenon, adopted early in life and then refined over weeks, months and years; a familiar yet seemingly alien pastime that might be considered a rational response to difficult, sometimes impossible, circumstances. The individuals discussed here were not consumed with self-hatred, so that their every waking moment was geared towards self-injury. On the contrary, several of the group were blessed with healthy family backgrounds and secure, loving relationships, the basis, perhaps, to avoid sinking into self-injury. Their life histories, however, contained clues as to their capacity for purposeful, physical damage of their own bodies, which were complicated further by the learning disability and lack of effective communication.

Sarah's misfortunes ploughed a furrow to self-injury, she was bright, frustrated and full of rage; Alison was wily and astute, her demeanour disconcerting and humour a little sly, though 'the banging never stops' (Mrs Wilson). Her utilization of 'London Bridge is Falling Down' brings to mind Sinason's (1992) observation of the purpose of a self-injurious boy's distorted, guttural version of 'Old MacDonald', suggesting both the animal noises and feelings in him, and also testing her as to whether she could discern that it was not his ordinary singing voice (p. 122/3). Lesley was complex and mercurial, trapped in a body that confirmed her feelings of uselessness, yet possessing of a clearly evident femininity and hopes that could be never realized. Sam appeared content in his own world, rarely sought company and comfort from others, observing Goffman's (1959: 243) dictum that 'life may not be much of a gamble, but interaction is'; he was charismatic, attractive and accumulated the most breaks, bruises and injuries of the group. Daniel and Janine were damaged in more conventional ways, through neglect, abuse and rejection, crushing weights that remained, despite being popular, loved and well cared for in their current lives. 'Everyone in some measure wears a mask, and there are many things we don't put ourselves into fully' (Laing 1959: 95); self-injury was central to the lives of the group, but they also teased, manipulated, charmed and infuriated when the occasion required it. Self-injury could provide temporary respite or oblivion, reasonable means of coping with unpleasant circumstances, memories and feelings; a 'primal' route to punishment, withdrawal, relief, control, confirmation of being alive. None of the group resented spending time alone, and only some of that time would be engaged in violence; but there were times when they inhabited what Bellow (1953) refers to as that 'rock depth of heavy trouble where the great majority of human beings spend much of their silent time'.

Realization of difference

The nature of intelligence was raised frequently, sometimes through parental certainty, enigmatic correspondence between psychologist and Mrs Anderson, or implicit in Sarah's silent rage, Daniel's cursory glance and Alison's cunning. This was manifested most clearly in tacit recognition of one's own difference, sometimes starkly, as in the contrast in ability between Lesley and her brother, though usually more insidiously. Additional physical difficulties were significant (see Table 1), and the consequent limitations, small stature and exaggerated effects internalized early in life, the construction of what was safe, free of anxiety, unlikely to make them feel bad. The development of a strong maternal relationship was evident with Lesley, Sam, Alison and Sarah, comprised subtleties of communication, deep knowledge of behavioural intricacies and marked anticipatory skills. The absence of language made this central relationship unique, the correct interpretation of behaviour defined and set it apart (Cogher 2005). Furthermore, Merleau-Ponty (1962) warns us to beware 'the ruse of language', and others argue that the spoken word is not a pre-condition for thought and reflection, 'though the character and quality...may not be available to us' (Goode 1994: 97). It has long since been pointed out that people with severe learning disabilities can have intense, emotional and elaborate relationships (MacAndrew & Edgerton 1966). Many of the relationships with parents were clearly rich, complex, maturing and multi-faceted; there was little evidence that they were repeated with others to the same degree, though Sam, Janine, Daniel and Alison were loved by many.

Conclusion

The self-injuring career offers a way of explaining behaviours frequently described as inexplicable or even alien as perhaps intelligible within the context of the individual's life history. The self-destructive impulses of those who choose more conventional means to pursue oblivion attract explanations aimed at understanding the burden of these damaged souls. People with severe learning disabilities appear less likely to be afforded such respect, their actions regarded with incredulity, somehow less rational. The argument presented here is that their self-injury is perfectly rational, perhaps it is the nature of the learning disability that we are yet to fully understand. The additional element of self-awareness, that dawning recognition of one's own difference, complicates issues further. Self-injury is hardly inevitable once the limitations imposed by the presence of a significant learning disability is understood by the individual, but its selection as a legitimate means for engaging with life on one's own terms should not be dismissed. It provides an existential component to a phenomenon that would benefit from comprehension as a valid way of coping with a difficult set of life circumstances, just as many of us choose similarly destructive but apparently more reasonable ways of coping with the human condition.

The functional approach to self-injury has resulted in the development of an impressive behavioural armoury, the biological explanation continues to present possibilities, and interdisciplinary cooperation is increasingly the way forward. Individuals with significant learning disabilities might select self-injury as a response to traumatic life histories, not necessarily involving rejection, sexual or physical abuse, or even witnessing violence or alcoholism, though this may apply to some, and the true experience of others may never be known. They might experience being chronically invalidated as persons, since the history of marginalized groups, Goffman's (1963) 'less than human', particularly people with learning disabilities, suggests this to be the case. Rage, self-loathing, shame, low self-worth and guilt, plausible responses to confirmation of regular failure, uselessness, parental disappointment, irrespective of love and security; 'as we experience the world, so we act' (Laing 1967: 117). The approach to understanding the reasons for damaging one's own body developed within the framework of self-harm seems to offer much to our understanding of the relationship between learning disability and self-injury. The research presented in this article suggests, for example, that the presence of a learning disability would not necessarily preclude an individual from emotionally shutting down and dissociating from the body as they engage in frenzied self-injuring. Furthermore, emotional overload might represent a reasonable response to feelings of extreme anger and anxiety. People with learning disabilities are well equipped with the need for emotional neutrality as a means of dealing with life's difficulties. Self-injury had become a dependable mechanism for dealing with everything, varying according to degree of contentment with life, but remaining a constant across time and space.

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